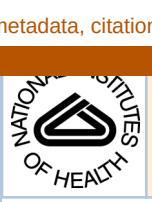

Published in final edited form as:

J Gerontol B Psychol Sci Soc Sci. 2008 May ; 63(3): S171–S183.

Emotional and Physical Health of Informal Caregivers of Residents at the End of Life: The Role of Social Support

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Abstract

Objectives—The objectives of this study were to examine the relationship between selected decedent and caregiver characteristics, facility-related perceptions, and emotional and physical health of 434 informal caregivers (94% family) of recently deceased residents of residential care/assisted living facilities and nursing homes. We also examined potential mediating effects of social support (informal, staff, and spiritual).

Methods—We analyzed data using linear mixed models.

Results—Among caregivers, younger age, female gender, more education, financial burden, other dependents, poorer perceptions of care, and more care involvement were associated with more emotional strain. More staff support also was associated with more emotional strain and partially mediated the relationship between having a trusted staff member and emotional strain. Characteristics associated with poorer physical health included unemployment, financial burden, poorer physician communication, and trusted staff member. Informal social support was directly related to better physical health and mediated the relationships between physical health and both physician communication and financial burden.

Discussion—Many characteristics related to end-of-life caregiving outcomes in long-term care are consistent with community-based studies, suggesting that end-of-life caregiving outcomes in long-term care are not markedly different than in other settings. However, the role of staff support may either facilitate or complicate emotional strain and merits additional study.

Keywords

End of life; Long-term care facilities; Social support; Emotional and physical health

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The role of families in providing care to older adults with chronic disease and/or disability is well established. Family and other informal caregivers including friends and neighbors often provide care along a trajectory or caregiving career that includes providing care to an older family member in the community, providing care in a long-term-care (LTC) facility, and providing care at the end of life (EOL; Gaugler, 2005; Montgomery & Kosloski, 2000; Pearlin & Aneshensel, 1994). Although researchers know that care is typically provided across settings and progressive levels of need, most research has focused on community-based caregiving. Thus, little is known about the experiences of informal caregivers who provide care for residents in LTC facilities, and even less is known about the experiences of informal caregivers who provide care to LTC residents at the EOL (Haley et al., 2002; Tornatore & Grant, 2004; Zarit, 2004). Consequently, although it is well documented that providing community-based care is associated with poor caregiver health outcomes (Dilworth-Anderson, Goodwin, & Williams, 2004; Pinquart & Sörensen, 2003; Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlon, 2003), research on informal caregivers' health outcomes when care recipients are residents of LTC and/or at the EOL has received little attention.

Community-based caregivers report poorer emotional health outcomes (depression, anxiety, role strain) during caregiving and more difficult bereavement after the death of the care recipient than noncaregivers (Knight & McCallum, 1998; Schulz et al., 2004). In terms of physical health, researchers have documented lower immunity, poorer self-reported health, and impaired functional health among caregivers (Kiecolt-Glaser et al., 2003; von Kanel et al., 2006). Furthermore, although both poorer caregiver emotional and physical health have been associated with placement of relatives in LTC (Yaffe, Fox, & Newcomer, 2002), evidence is mixed as to whether LTC placement is associated with improvements in caregivers' health. Some researchers have documented sustained improvement in emotional (Mausbach et al., 2007; Zarit & Whitlatch, 1992) and physical (Mausbach et al., 2007) outcomes following placement, but others have suggested that placement is not associated with improved emotional (Schulz et al., 2004) or physical (Lieberman & Fisher, 2001) health among caregivers.

Although it is logical, and some empirical evidence supports the fact, that burdens and strains are at their greatest during the EOL period (Herbert, Prigerson, Schulz, & Arnold, 2006; Phipps, Braitman, True, Harris, & Tester, 2003; Wolff, Dy, Frick, & Kasper, 2007), this is the period in the caregiving trajectory about which researchers know least. Given that approximately 1 in 4 Americans and 70% of adults with dementia die in LTC facilities (Mitchell, Teno, Miller, & Mor, 2005; Teno et al., 2004), and that LTC facilities are increasingly the site of EOL care for older Americans (Mitchell et al., 2005; Munn, Hanson, Zimmerman, Sloane & Mitchell, 2006), knowing more about the experience of EOL care in these settings is especially important. Furthermore, although scholars know that resources such as social support reduce a host of negative outcomes for caregivers in the community, they know less about social support for informal caregivers who provide care in LTC facilities and, again, even less about those providing care for residents at the EOL.

Social support varies along a host of dimensions, one being whether it is informal or formal. Caregivers of community-based older adults typically receive the majority of their support from informal sources such as family and friends and/or other unpaid helpers; they tend to use limited formal or paid support (Cox & Monk, 1993; Norgard & Rodgers, 1997; Wolff & Kasper, 2006). This situation is different in LTC, however, where staff provide formal support that is important in the context of adjusting to the LTC setting, family involvement, and family satisfaction (Friedemann, Montgomery, Maiberger, & Smith, 1997; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Furthermore, it may be that the presence of formal

support provided by LTC staff changes the amount and/or type of informal support that family caregivers of residents in LTC facilities receive from others.

This study used a stress and coping model to examine the emotional and physical health of informal caregivers of LTC residents at the EOL (see Figure 1). The stress and coping model posits that combinations of background characteristics (in this case, decedent and caregiver characteristics), stressors (primary and secondary), and mediators influence an individual's reaction to stress (Pearlin, Mullan, Semple, & Skaff, 1990). We examined whether selected decedent and caregiver characteristics and facility-related perceptions were associated with emotional and physical health, and whether three sources of social support (informal, staff, spiritual) helped explain these relationships.

The model proposes that primary stressors (especially chronic stressors) beget secondary stressors, a process referred to as *stress proliferation* (Pearlin & Aneshensel, 1994). Primary stressors are related to the cognitive and physical needs of care recipients and also to the surveillance and work required to ensure care recipients' safety (Pearlin et al., 1990). In LTC settings, such surveillance involves monitoring the resident's care through visitation and involvement in care. These stressors are objective and indicate the demands of care; other primary stressors are subjective and reflect how caregivers experience the situation (Aneshensel, Pearlin, & Schuler, 1993; Pearlin et al., 1990; Pearlin, Aneshensel, & LeBlanc, 1997; Tornatore & Grant, 2004). Subjective primary stressors can include the overall perceptions of care and perceived quality of the death experience.

Secondary stressors are produced as a result of primary stressors and are associated with roles and activities outside the caregiving situation. Such stressors include family and/or job conflict as well as stress related to financial and/or social limitations. The model proposes that in the face of stressors (primary and secondary), potential mediators such as social support help explain the relationship between stressors and emotional and physical health outcomes. For example, this suggests that caregivers who have stress such as financial burden, but also more social support, will experience comparatively better health than if they did not have such support.

Similar to other studies using the stress and coping model, we examined social support as a mediator between stressors and health outcomes. Our primary research questions were the following: (a) What is the relationship between potential stressors (defined as selected decedent and caregiver characteristics and facility-related perceptions) and the caregiver's emotional and physical health in the context of EOL caregiving? (b) Does social support (informal, staff, spiritual) mediate the relationship between potential stressors and emotional and physical health?

Methods

As part of a study of EOL care in residential care/assisted living (RC/AL) settings and nursing homes (NHs), a stratified random sample of 230 LTC facilities (199 RC/AL facilities and 31 NHs) was recruited in four states (Florida, Maryland, North Carolina, and New Jersey) to participate in the Collaborative Studies of Long-Term Care (Zimmerman et al., 2001). To identify decedents and contact their family and staff caregivers, researchers contacted participating facilities each month and asked them to identify resident deaths that had occurred during the previous month. A decedent was eligible if he or she had resided in the facility for at least 15 of 30 days prior to death and had died within the facility or within 3 days of leaving the facility by transfer or discharge to another facility. For each eligible death, facility staff identified the family member or responsible party who was most involved in decisions for the deceased resident during the last month of life and who had

visited and/or spoken with the resident or staff at least once during the last month of life. A letter of condolence and a consent form introducing the study were mailed 4 weeks after the date of death to the identified family member or responsible party. Data were collected through telephone interviews, with verbal consent obtained prior to conducting interviews. The institutional review board of the University of North Carolina at Chapel Hill approved all procedures.

Between July 2002 and January 2005, family interviews were completed for 451 decedents (44% of eligible decedents; 68% of those for whom a family member was identified by the facility and could be contacted within a 6-month window). Slightly less than three quarters (74%) of the interviews were completed within 4 months post death, and almost all (97%) were completed within 6 months post death. The caregiver sample for this study included the 434 decedents whose informal caregivers provided complete information on the health outcomes of interest in this study.

Measures

The dependent variables were emotional and physical health. The emotional health measure was a 7-item indicator of strain that assessed the stress and strain a caregiver felt as a result of having a relative in an NH (Whitlatch et al., 2001). Examples of questions include the following: “I don’t have enough time for myself,” “I have more things to do than I can handle,” “I feel that my social life is limited,” and “I have trouble managing all the demands on my life.” Caregivers chose between four response options: (1) strongly disagree, (2) disagree, (3) agree, and (4) strongly agree. Possible scores ranged from 7 to 28, with higher scores indicating greater emotional strain (Cronbach’s $\alpha = .89$ for this sample).

The physical health measure was the 5-item general health subscale of the Medical Outcomes Study (McHorney, Ware, Lu, & Sherbourne, 1994). Caregivers rated their health as either excellent, very good, good, fair, or poor. In addition, caregivers responded to four statements concerning their health in relation to others’ and their expectations about their health. We used an established algorithm to convert responses to a percentile score, with possible values ranging from 0 to 100 (Ware & Sherbourne, 1992). For this study, we recoded the values so that higher scores indicated poorer health (Cronbach’s $\alpha = .82$ for this sample).

Background characteristics included the decedent’s age, gender, race, and length of stay in the LTC facility in which the resident had died or from which he or she had been transferred within 3 days of death. We also included the informal caregiver’s age, gender, race, marital status, relationship to the decedent, level of formal education, employment status, and number of other dependents. Dependents were those for whom the respondent had provided primary physical and/or financial support during the last month of the decedent’s life.

Potential primary stressors were decedent and caregiver characteristics selected based on theory and existing literature (Mitrani et al., 2006; Pinquart & Sörensen, 2003; Scharlach, Li, & Dalvi, 2006; Schulz & Beach, 1999; Tornatore & Grant, 2002). Decedent stressors were objective (those related directly to the health of the decedent during the last month of life) and included cognitive status (impaired vs intact) and a symptom burden score based on the caregiver’s perception of the decedent’s severity and frequency of symptom occurrence in four areas during the last month of life: pain, shortness of breath, skin cleanliness, and nutrition. Scores for each area ranged from 0 to 9, and each area was equally weighted. We summed scores to provide a total score ranging from 0 to 36, with higher scores indicating greater symptom burden (Hanson et al., 2008). We also included the course of illness in the last year of life (stable health; steady, slow decline in health; a series of ups and down in health).

Facility-related primary stressors were both objective (those related to surveillance and monitoring) and subjective (reflecting how caregivers experienced the situation). Figure 1 lists the primary objective stressors of family–physician communication, number of days the caregiver visited the resident during the last month of life, and level of involvement. Family–physician communication was assessed using a 7-item scale (Cronbach's $\alpha = .96$ in this sample; Biola et al., 2007). Caregivers also reported their perceived level of involvement (one item, with five response options ranging from very low to very high). Other potential facility-related stressors were conceptualized as primary subjective stressors and included the caregivers' perception of the overall care the decedent had received in the last month of life (poor, fair, good, very good) and the effectiveness of hygiene care (not at all, a little, quite a bit, very much). For analysis purposes, poor hygiene care was any response lower than "very much." Also, caregivers responded whether they would have preferred more involvement, no change in involvement, or less involvement in the resident's care and whether they had a trusted relationship with any facility staff member (yes/no).

Experiences related to the death of the residents were conceived as primary objective stressors and included the informal caregiver's report of hospice enrollment (yes/no), whether the resident had died in the facility (yes/no), whether family was present at the time of death (yes/no), and whether the death was expected by the informal caregiver (yes/no). In addition, caregivers rated the overall quality of death (conceived as a primary subjective stressor) using a 5-point scale (not at all true to completely true) in response to the following question: "How would you rate the overall quality of [his or her] death; in other words, how much was it like he/she or the family wanted it to be?"

Potential secondary stressors, or those stressors that are triggered by primary caregiving stressors but experienced outside the caregiving role, included the number of other helpers, financial burden, and family conflict. Thus, caregivers indicated the number (none, one, two or more) of other helpers who were available to them in the last month of the decedent's life. Financial burden was the extent (not at all, a little, quite a bit, very much) to which caregivers felt a burden associated with facility fees or health care costs during the last year of the decedent's life. The family conflict measure consisted of eight items (Gaugler, Zarit, & Pearlin, 1999). Respondents indicated the amount of disagreement (none, a little, quite a bit, a lot) regarding the decedent's care during the last month of life in response to statements such as "They gave you unwanted advice." We averaged item scores for a total score (range 0 –3), with a higher score indicating more disagreement (Cronbach's $\alpha = .95$ in this sample).

Potential mediators in this study included three sources of social support: informal, staff, and spiritual. The Medical Outcomes Study Social Support Survey was used to assess informal social support (Sherbourne & Stewart, 1991). It includes 19 items that assess four types of support (emotional/informational, tangible, positive social interaction, and affectionate). For each item, respondents indicated how often the type of support was available to them during the last month of the decedent's life, ranging from 1 = none of the time to 5 = all of the time. Scores ranged from 19 to 95, with higher scores reflecting more support.

Staff social support was based on a nursing assistant support for families scale (Whitlatch et al., 2001). An example of 1 of its 11 items is "How often did staff members (not including physicians) reassure you that your family member's behavior was not unusual?" Item scores ranged from 0 = never/almost never or no instance to 3 = always/almost always. We summed item scores for a scale score ranging from 0 to 33. A higher score indicated more support. Spiritual support was measured with five items from the Systems of Belief Inventory (Holland, Kash & Passik, 1998), with a sample question being "When I needed suggestions on how to deal with problems, I knew someone in my religious or spiritual

community that I could turn to." Respondents indicated agreement ranging from 0 = strongly disagree to 3 = strongly agree, for a total range of 0 to 15. Higher scores indicated more support. Fewer than 10 caregivers indicated they had no spiritual community.

Analysis

We used descriptive statistics to characterize the sample with respect to decedent and informal caregiver characteristics, potential stressors, mediators, and the physical and emotional health measures. We used linear mixed models, implemented using the SAS MIXED procedure, to account for the clustering of respondents within facilities by specifying a random effect for facility (Littell, Milliken, Stroup, Wolfinger, & Schabenberger, 2006; Verbeke & Molenberghs, 2000). We first estimated a model for each independent variable and each health outcome. We selected for inclusion in a multivariable model for each health outcome the informal caregiver and resident characteristics and potential stressors that were associated with each health outcome in these bivariate analyses ($p < .10$). We eliminated variables no longer at least marginally significant ($p < .10$) in the multivariable model once we were assured, via examination of correlation matrices, that this was not due to near collinearity among the independent variables.

Tests for mediation of the direct effects identified in the multivariable models followed the regression strategy outlined by Frazier, Tix, and Barron (2004). We tested whether each independently associated informal caregiver and resident characteristic was associated with each potential mediator by regressing the potential mediator separately on each characteristic. For predictor-mediator combinations that met this requirement, we examined potential mediation effects by adding the potential mediators to the multivariable model for each outcome and computing the percent change in the coefficient for each independent variable.

In order to be considered a mediator, the social support measure also had to be associated with the health outcome measure while we controlled for the selected informal caregiver and resident characteristics (Frazier et al., 2004). Finally, for the emotional health outcome, which had two social support measures meeting criteria for mediation, we estimated a model including the significant resident and informal caregiver characteristics and both mediators. Based on previous empirical and theoretical research supporting potential mediation by social support, we used a fairly liberal p value ($p < .10$) in determining that the predictor–mediator and mediator–outcome relationships were statistically significant.

Results

Caregivers for residents at the EOL in this sample were primarily female (72%) and adult daughters or daughters-in-law (49%); 19% were adult sons or sons-in-law, 9% were spouses, 18% were other family, and 5% were friends and neighbors (see Table 1). In addition, caregivers were on average 60 years old; were predominantly White, non-Hispanic (91%), and had at least some college education (79%). In terms of other roles, 64% were married, 58% were employed, and 62% reported they had one or more dependents.

Most (79%) of the decedents were cognitively impaired and most (68%) had experienced a steady, slow decline in health before death. Caregivers reported visiting the LTC facility an average of 15.5 times during the decedent's last month of life. In all, 52% perceived that their level of involvement was very high during the last month of life, 26% perceived it as high, 15% perceived it as moderate, and 7% perceived it as low or very low.

As shown in Table 2, the mean emotional strain score was 18.5 ($SD = 5.4$; range 7–28), and the mean recoded physical health score (higher scores equal poorer health) was 24.4 ($SD =$

16.1; range 0–100). Caregivers reporting more emotional strain tended to report poorer physical health, although the strength of the association was modest ($r = .20$, $p < .001$). In terms of social support, the mean informal support score was 84.7 ($SD = 20.0$; range 0–100), mean staff support score was 20.3 ($SD = 8.1$; range 0–33), and mean spiritual support score was 7.9 ($SD = 5.5$; range 0–15).

Association of Characteristics, Potential Stressors, and Mediators With Emotional Strain

Direct effects—Table 3 lists the bivariate associations of all variables with the outcomes under study. We entered into the multivariable model those that were marginally significant ($p < .10$) at the bivariate level. Findings based on the multivariable model indicated that men and older caregivers reported less emotional strain (see Table 4). Furthermore, White Hispanics reported less strain than did White non-Hispanics, and those caregivers with less than a high school degree reported less emotional strain than did those with a college degree.

As shown in Table 4, facility-related primary stressors associated with increased emotional strain included visiting the facility more often in the last month of life, high reported levels of involvement, and a perception that the overall quality of care was less than very good. In addition, those reporting having a trusted staff member had increased emotional strain, though this relationship was only marginally statistically significant ($p = .072$) in the multivariable model. Secondary stressors associated with increased emotional strain included family conflict and financial burden. There was a positive relationship between staff support and increased emotional strain, and there was a trend indicating that caregivers with higher levels of informal social support reported lower levels of emotional strain ($p = .069$). Spiritual support was not associated with emotional strain in the multivariable model.

Although in the bivariate analyses caregiver emotional strain was associated with shorter decedent length of stay, more symptom burden, and a fluctuating course of illness (see Table 3), these did not remain significant in multivariable analyses predicting emotional strain. Other characteristics that were statistically significant in the bivariate analyses but were not independently associated with emotional strain in multivariable analyses were caregiver relationship and marital status, employed informal caregiver (likely due to the association with age), report of poor hygiene care and a poorer global assessment of quality of death (likely due to their association with the global assessment of quality of care), informal caregivers preferring a different amount of involvement (likely due to this measure's association with perceived level of actual involvement), and hospice care as part of the death experience.

Mediation effects—In order to assess mediation by the social support measures, we first regressed each of the potential mediators on each of the background characteristics and stressors that were independently associated with emotional strain. For those relationships that were at least marginally significant, we computed the percent change in the regression coefficient for the characteristic or stressor upon addition of the potential mediator to the model. Because spiritual support was not associated with emotional strain in the multivariable model ($p = .178$), we did not include this type of social support in the assessment of mediation.

As shown in Table 4, analyses identified no mediation effects for informal social support, and indeed informal social support was itself only marginally significantly associated with emotional strain when we adjusted for all of the background characteristics and stressors. However, staff support partially mediated the relationship between having a trusted staff member and increased emotional strain (20%–30% decrease in the coefficient). Such a reduction in the regression coefficient with adjustment for staff support indicated that the trusted staff member relationship with emotional strain may have been mediated through

staff support: Those who had a trusted staff member had more staff support, which was in turn associated with more emotional strain.

The addition of staff support to the regression model also affected the relationship between perception of quality of care as less than very good and emotional strain (59%–66% increase in the coefficient). There was an inverse relationship between staff support and quality of care ratings; hence, the strength of the relationship between lower care ratings and emotional strain was enhanced by adjustment for staff social support.

Association of Characteristics, Potential Stressors, and Mediators With Poor Physical Health

Direct effects—Similar to the analyses for emotional strain, we entered into the multivariable model for poor physical health background characteristics and potential stressors that were marginally significant ($p < .10$) at the bivariate level (see Table 3). Findings based on the multivariable model indicated that employed caregivers reported better physical health (i.e., lower levels of poor health) than those who were not employed (see Table 5). In terms of primary stressors, a higher rating of physician communication was also associated with better physical health. However, having a trusted staff member was associated with poorer physical health, and caregivers who reported financial burden (a secondary stressor) also reported poorer physical health. More informal support was related to better physical health. Neither staff support nor spiritual support had a direct relationship with physical health, so we did not further evaluate these for mediation effects.

Mediation effects—The addition of informal support to the model helped to explain the relationship between perception of better physician communication and better physical health (24% decrease in the coefficient; see Table 5). Informal support also functioned as a mediator between financial burden and poor physical health (17% decrease in the coefficient).

Discussion

This study evaluated informal caregivers' reports of their experiences during the last month of life of residents in LTC—a critical but growing and little-studied cohort of caregivers. More specifically, this study evaluated the relationship between caregivers' emotional and physical health and a variety of characteristics related to the decedent and caregiver, and facility-related perceptions. Similar to most informal caregivers of older adults, the caregivers in this study were primarily female family members who had other dependents (62%), and they remained highly involved in the care of their family members, visiting roughly one half of the days in the last month of life (Gaugler, Anderson, Zarit, & Pearlin, 2004; Port et al., 2005). Among the stressors experienced by these caregivers were absence of other helpers (45%) and financial burden related to caregiving (40%).

Our findings that older caregivers, men, and those with lower levels of education reported less emotional strain are consistent with findings from other studies (Amirkhanyan & Wolf, 2003; Bowman, Mukherjee, & Fortinsky, 1998; Cameron, Franche, Cheung, & Stewart, 2002; Pinquart & Sörensen, 2007; Thornton & Travis, 2003; Williams, 2005). The positive relationship between family conflict, financial burden, presence of other dependents, and emotional strain is also consistent with other empirical evidence (Scharlach et al., 2006; Strawbridge & Wallhagen, 1991; Tremont, Davis, & Bishop, 2006). In general, caregivers with poorer family functioning (e.g., family conflict, burden) reported poorer emotional health. The fact that these relationships remain evident during the EOL in LTC suggests that they are pervasive throughout the caregiving career.

It is no surprise that employed caregivers reported better physical health (i.e., lower levels of poor health), as it is reasonable that caregivers with the ability to manage the role of employee in addition to their caregiving role would need adequate health to do so. Conversely, financial burden, which may be linked to absence of employment, was associated with poorer health. Findings also indicated that caregivers who were more likely to report having a trusted staff member were in poorer physical health. It may be that their poorer health status required them to develop more trusting relationships with the staff.

Researchers have previously documented the association between better communication with the physician and better physical health for patients, but not for family caregivers (Franks et al., 2005). However, physician communication, or more specifically time spent discussing advance directives, has been associated with greater satisfaction of family caregivers with EOL care for NH residents (Engel, Kiely, & Mitchell, 2006). In this study, the seven items on the communication measure assessed the degree to which the caregiver had been kept informed and understood the resident's condition, received information about what to expect, was able to ask questions, and felt listened to and understood by the physician. Thus, it would seem that they would be as likely to relate to emotional strain as to physical health, and the fact that they related only to the latter suggests that being able to communicate with physicians requires better physical health rather than results in it. This association between communication and caregiver health provides additional support to recent studies calling for improved physician–family communication for persons who are or may be dying in LTC (Biola et al., 2007; Wetle, Shield, Teno, Miller, & Welch, 2005).

In adjusted analyses, none of the decedent primary stressors were related to emotional or physical health of the caregivers in this sample. Researchers have reported similar findings about the relative lack of importance of care recipient factors in community-based samples (Dilworth-Anderson et al., 2004; Harwood, Barker, Ownby, & Duara, 2000) and also in NHs. Tornatore and Grant (2002), for example, found that resident characteristics were not associated with family caregiver burden, stating that there is "growing evidence that care recipient impairment is not as important as other factors in caregiver outcomes." These results suggest that interventions aimed at improving family caregiver health do not need extensive tailoring based on care recipient characteristics but instead should concentrate on characteristics of the caregivers and the caregiving environment.

Although decedent stressors were not related to health outcomes, facility perceptions and secondary stressors were important. Facility-related stressors such as poorer quality of care, days visited, and caregiver involvement were associated with increased emotional strain, which supports other findings that more involved caregivers report higher levels of emotional distress (Whitlatch et al., 2001). Furthermore, our findings support the stress and coping conceptualization that secondary stressors (i.e., those outside the caregiving role) are critical to understanding outcomes for caregivers. Two of the three secondary stressors (financial burden and family conflict) were related to more emotional strain, and financial burden was related to poorer health. Once again, this study clarifies the consistency of these relationships throughout the EOL of the care recipient and the relevance of a stress and coping model to understanding caregiving for residents at the EOL.

The role of the potential mediators was mixed and, in the case of staff support, somewhat surprising. If staff support were indeed a resource, empirical and theoretical evidence suggests that it would be associated with less emotional strain. However, our data indicate a direct link between staff support and increased emotional strain. A more detailed examination of the content of the staff support items showed that the staff support measure assessed staff communication skills, such as listening, keeping the family member informed, encouraging the family to talk about concerns, and providing support in dealing with

feelings about death. One possible explanation for this finding is that staff support increases family awareness of the impending death, thus increasing emotional strain. Whereas Vohra, Brazil, Hanna, and Abelson (2004) documented that informal caregivers value when staff are able to inform them that death is near, staff should consider that such knowledge may be associated with increased strain (Goodridge, Bond, Cameron, & McKean, 2005). Alternatively, one cannot infer the temporal relationship between staff support and emotional strain from this cross-sectional study; it is also plausible that those who experienced emotional strain may have been more likely to receive staff support.

Staff support mediated the relationship between having a trusted staff member and emotional strain, as evidenced by the fact that the regression coefficient for having a trusted staff member was reduced when staff support was added to the regression model. This finding suggests that having a trusted staff member is associated with increased staff support, which is in turn associated with more emotional strain. Thus, the association between having a trusted staff member and increased emotional strain is partly explained by the positive relationship of staff support with both having a trusted staff member and emotional strain.

Staff support had the opposite effect on the relationship between poorer quality of care and emotional strain, however. Here, because of the inverse association between poor quality care and staff support and the positive relationship between staff support and emotional strain, the addition of staff support to the regression model magnified the relationship between poorer quality of care and emotional strain. Again, when one considers that the staff support measure was related to talking about death and communication skills, it is not a surprise that caregivers who perceived poorer quality of care would be more strained when they had increased awareness and communication regarding the impending death of their family member. However, because we cannot infer causality, it may also be that caregivers who were more strained perceived that the quality of care was poorer.

Similar to other findings in the social support literature, more informal support was related to better physical health. In addition, the mediating function of informal support on the relationship between secondary stressors such as financial burden and poor physical health is consistent with Pearlin and colleagues' stress and coping model. The potential mediator of spiritual support was not related (either directly or as a mediator) to either health outcome in this study. This may be because members of one's spiritual community may be less likely than family and friends or LTC staff to know about the frail condition of a care recipient in an LTC facility. Furthermore, the items in the spiritual support measure (e.g., "When I needed suggestions on how to deal with problems, I knew someone in my religious or spiritual community that I could turn to," "I sought out people in my religious or spiritual community when I needed help") necessitated that the caregiver seek out support from his or her spiritual community. Neither the informal nor staff support measure required the caregiver to seek support, but rather they reflected others' (family, friends, staff) responses to the caregiver.

Each of these variables and the hypothesized relationships are shown in Figure 1, which is a modification of Pearlin and colleagues' stress and coping model (Aneshensel, Pearlin, & Schuler, 1993; Pearlin et al., 1990; Pearlin & Aneshensel, 1994; Pearlin, Aneshensel, & LeBlanc, 1997) applied to informal caregivers who provide care to dying residents in LTC facilities. This modification is also based on the work of Whitlatch et al. (2001) and Tornatore and Grant (2002) and advances theories of stress and coping by the addition and detailed examination of facility-related perceptions and the inclusion of staff support as a potential mediator.

Findings related to facility perceptions suggest that additional study is needed to more fully understand caregiver involvement. That is, although other evidence indicates that involvement of informal caregivers in LTC facilities is related to improved resident and caregiver outcomes, our finding that more involved caregivers report more emotional strain suggests a need to better understand caregivers' reasons for involvement and also their emotional needs. Thus, future conceptualization of the stress and coping model to EOL caregiving in LTC should include a measure of bereavement. A bereavement measure could help identify caregivers who are at risk for complicated bereavement and contribute to understanding the relationship between bereavement and the health outcomes of informal caregivers.

This study is one of the first large studies to examine stressors, outcomes, and social support for informal caregivers who provide care for residents in NHs and RC/AL settings at the EOL. As such, it provides new insight into this group of caregivers and their experiences at a critical point in the caregiving trajectory. There are, however, some limitations to the study. First, of 1,020 eligible deaths, 667 identified caregivers were successfully contacted. No family caregiver was identified by the facility ($n = 123$), or the caregiver could not be reached during the study enrollment period ($n = 230$) for the other eligible deaths. Among the 667 caregivers who were contacted, a total of 216 caregivers refused to enroll in the study, and 17 who participated did not complete the items on caregiver health. Therefore, analyses were restricted to the 434 informal caregivers who consented to be interviewed and responded to the emotional and physical health items (response rate = 65%).

In comparing participants and nonparticipants, we found that caregivers of decedents from larger facilities and NHs, and of younger or Black decedents, were less likely to participate. Although this should not strongly affect the associations between variables, it could mean that our overall estimates of caregiver health are biased if, for example, caregivers we were unable to contact or who refused to participate were in poorer emotional or physical health than those who participated. Such a reduction in variability might have limited our ability to identify statistically significant associations. Second, ours was a cross-sectional study, so we cannot determine temporality and causality. Finally, given that this was a retrospective study, the responses were indicative of the caregiver's feelings after the death and could have been affected by the caregiver's bereavement.

Our modification of the Pearlin et al. stress and coping model (as represented in Figure 1) does, however, identify both potential caregiver stressors and resources associated with the emotional and physical health of informal caregivers of LTC residents at the EOL. These include certain background variables (employment, education), primary stressors (quality of care), secondary stressors (financial burden), and social support (informal, staff). The role of staff support in ameliorating or exacerbating caregiver stress is difficult to interpret and presents an opportunity for additional research regarding the nature of and outcomes associated with staff/family communication and support. We concur with Whitlatch et al. (2001) that there is much to learn about the complex nature of interactions within LTC settings. Given that deaths in LTC facilities are expected to increase and that families of these decedents will be under stress, it is imperative that researchers better understand characteristics that increase and alleviate this stress so as to provide better care not only for facility residents who are terminally ill, but also for the family members who continue to be actively involved in that care.

Acknowledgments

This work was funded by Grants R01 AG18967 and K02 AG00970 from the National Institute on Aging. We thank the staff, residents, and family members who participated in the Collaborative Studies of Long-Term Care for their time and commitment to learning more about and improving the quality of life in assisted living/residential care

communities and nursing homes. Thanks also are given to Drs. Carol Whitlatch and Elizabeth Clipp for guidance on measures and conceptualization.

S. W. Williams was responsible for conceptualization of the manuscript and selection of measures specific to the manuscript and took overall responsibility for the manuscript. C. S. Williams was responsible for conceptualization and conduct of analyses and tables as well as overall completion and review of the manuscript. S. Zimmerman was responsible for conceptualization of the parent study and overall oversight and conduct of the parent study as well as conceptualization and completion of this manuscript. J. Munn participated in the Methods and Discussion portions of this manuscript and overall review of the manuscript. D. Dobbs participated in data acquisition, Methods, Discussion, and overall review of the manuscript. P. D. Sloane was responsible for conceptualization of the parent study and overall oversight and conduct of the parent study and conceptualization and completion of this manuscript.

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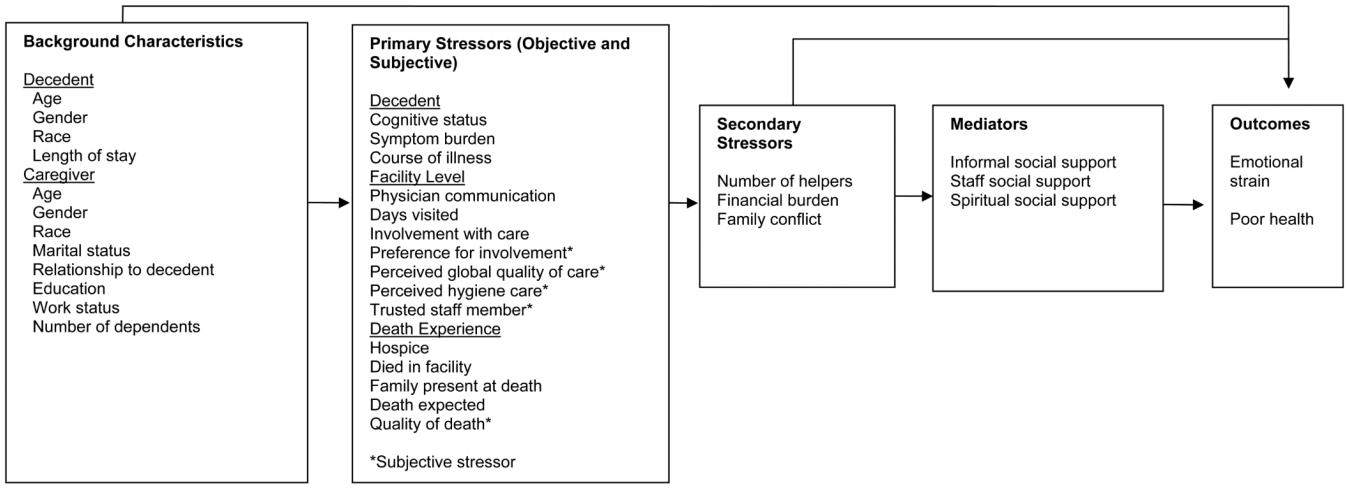

Figure 1.
Conceptualization of Stress and Coping Model for Informal Caregivers of Residents at the End of Life (based on Pearlin et al., 1990)

Table 1

Characteristics of Decedents and Family Caregivers and Distribution of Potential Stressors (N=434)

	n	Percent	Mean	(SD)
Background Characteristics				
Decedent Characteristics				
Age			86.0	(9.0)
Female	309	71.2%		
Race/Ethnicity				
White, non-Hispanic	394	90.8%		
White, Hispanic	8	1.8%		
Black	28	6.5%		
Other	4	0.9%		
Length of stay (months)			27.7	(32.3)
Family Caregiver Characteristics				
Age			60.4	(11.5)
Female	311	71.7%		
Race/Ethnicity				
White, non-Hispanic	393	90.8%		
White, Hispanic	9	2.1%		
Black	29	6.7%		
Other	2	0.5%		
Married	277	63.8%		
Relationship to decedent				
Spouse	37	8.6%		
Daughter/daughter-in-law	210	48.6%		
Son/son-in-law	83	19.2%		
Other family	78	18.1%		
Other	24	5.6%		
Education				
< High school	11	2.5%		
High school	81	18.7%		
Some college/trade school	129	29.7%		
College +	213	49.1%		
Working full or part-time	251	57.8%		
Potential Primary Stressors				
Decedent				
Cognitively impaired	340	78.5%		
Symptom burden (0-36)			18.0	(7.0)
Course of illness				
Stable health	42	9.7%		
Steady, slow decline	292	67.7%		

	n	Percent	Mean	(SD)
Series of ups and downs	97	22.5%		
Death Experience				
Received hospice	225	52.6%		
Died in facility	379	87.3%		
Family present at death	146	36.8%		
Death expected	228	52.8%		
Global assessment of quality of death (1-5)			4.0	(1.4)
Quality of Care				
Global assessment of quality of care				
Fair/Poor	44	10.2%		
Good	117	27.0%		
Very good	272	62.8%		
Poor hygiene care	140	32.9%		
Long-term Care Relationships				
Family trusted particular staff member	383	88.5%		
Family perception of physician communication (7 items, 0-3)			1.7	(1.0)
Number of other helpers				
None	193	44.7%		
One	123	28.5%		
2 or more	116	26.9%		
Amount of Involvement				
Days visited resident			15.5	(10.4)
Perceived level of involvement				
Very high	223	51.7%		
High	113	26.2%		
Moderate	65	15.1%		
Low or very low	30	7.0%		
Preference for involvement				
Be more involved	107	24.7%		
No change in involvement	310	71.6%		
Be less involved	16	3.7%		
Potential Secondary Stressors				
Number of dependents				
None	164	37.8%		
1	148	34.1%		
2	50	11.5%		
3 or more	72	16.6%		
Any financial burden in past year	174	40.4%		
Family conflict (8 items,0-3)			0.6	(0.9)

Table 2

Descriptive Statistics of Scales Used to Measure Caregiver Social Support, Emotional Strain and Physical Health (N=434)[a]

	Mean	(S.D.)	Median	% at minimum	% at maximum	Alpha
Sources of Social Support						
Informal Social Support (19 items, 0-100)	84.71	(19.98)	95	0%	38%	0.96
Staff Social Support (11 items, 0-33)	20.34	(8.05)	22	1%	4%	0.89
Spiritual Social Support (5 items, 0-15)	7.88	(5.48)	8	23%	19%	0.95
Caregiver's Health[b]						
Emotional Strain (7 items, 7-28)	18.51	(5.41)	18	5%	7%	0.89
Physical Health (5 items, 0-100)	75.63	(16.10)	76	0%	12%	0.82

[a] Sample size ranges from 425 to 434 due to missing data for some social support measures; all have complete data for caregiver health measures.

[b] Higher emotional strain scores indicate poorer emotional health, whereas higher physical health scores indicate better health.

Table 3

Bivariate Associations of Background Characteristics, Potential Stressors, and Social Support, with Health of Family Caregiver (N=434)[a]

		Emotional Strain			Physical Health		
	N	Mean or Correlation	(SD)	p-value [b]	Mean or Correlation	(SD)	p-value [b]
Background Characteristics							
Decedent Characteristics							
Age	434	r = −0.040		0.158	r = 0.058		0.241
Gender							
Male	125	18.0	(5.8)	0.349	75.7	(16.0)	0.847
Female	309	18.7	(5.3)	--	75.6	(16.2)	--
Race/Ethnicity							
White, non-Hispanic	394	18.5	(5.3)	ref[0.736]	75.5	(16.1)	ref[0.775a]
White, Hispanic	8	19.4	(7.7)		80.6	(15.3)	
Black	28	18.0	(5.7)		74.8	(17.0)	
Other	4	22.0	(5.0)		81.3	(15.6)	
Length of stay (months)	434	r = −0.173		<0.001	r = 0.019		0.642
Family Caregiver Characteristics							
Age	428	r = −0.340		<0.001	r = −0.085		0.099
Gender							
Male	123	16.9	(5.0)	0.004	77.1	(15.8)	0.218
Female	311	19.1	(5.5)		75.0	(16.2)	
Race/Ethnicity							
White, non-Hispanic	393	18.6	(5.3)	ref[0.091]	75.5	(16.1)	ref[0.929]
White, Hispanic	9	15.0	(6.2)	0.042	79.6	(14.8)	0.540
Black	29	18.0	(5.6)	0.734	75.5	(17.2)	0.889
Other	2	24.5	(4.9)	0.135	71.5	(6.4)	0.805
Married							
No	157	17.6	(5.2)	0.019	74.3	(16.9)	0.183
Yes	277	19.0	(5.5)	--	76.4	(15.6)	--
Relationship to decedent							
Spouse	37	16.4	(6.1)	0.009	70.7	(18.3)	0.071
Adult child	293	19.1	(5.3)	ref[0.002]	75.7	(16.3)	ref[0.090]
Other family	78	18.1	(5.2)	0.274	75.7	(14.5)	0.909
Other	24	15.8	(5.5)	0.003	81.5	(13.5)	0.107
Education							
High school or less	92	17.1	(5.7)	0.008	73.3	(14.6)	0.100
Some college/trade school	129	18.7	(5.3)	0.665	75.4	(16.8)	0.527
College +	213	19.0	(5.3)	ref[0.025]	76.8	(16.3)	ref[0.259]
Working full or part-time							
No	183	17.0	(5.1)	<0.001	73.1	(16.1)	0.008

		Emotional Strain			Physical Health		
	N	Mean or Correlation	(SD)	p-value [b]	Mean or Correlation	(SD)	p-value [b]
Yes	251	19.6	(5.4)	--	77.5	(15.9)	--
Potential Primary Stressors							
Decedent Characteristics							
Cognitively impaired							
No	93	17.7	(5.4)	0.199	76.0	(18.4)	0.937
Yes	340	18.8	(5.4)	--	75.5	(15.5)	--
Symptom Burden (0-36)	419	r = 0.159		0.004	r = −0.036		0.389
Course of illness							
Stable Health	42	16.5	(5.2)	0.001	73.3	(18.1)	0.604
Steady, slow decline	292	18.3	(5.2)	0.007	76.0	(16.1)	0.471
Series of ups and downs	97	20.1	(5.7)	ref[0.003]	75.0	(15.2)	ref[0.474]
Death Experience							
Received hospice							
No	203	18.0	(5.6)	0.043	76.1	(15.5)	0.536
Yes	225	19.1	(5.2)	--	75.2	(16.8)	--
Died in Facility							
No	55	19.1	(5.7)	0.398	77.3	(14.7)	0.434
Yes	379	18.4	(5.4)	--	75.4	(16.3)	--
Family present at death							
No	251	18.5	(5.3)	0.499	74.6	(14.9)	0.288
Yes	146	18.8	(5.7)	--	76.4	(17.8)	--
Death expected							
No	204	18.8	(5.5)	0.421	74.5	(15.3)	0.227
Yes	228	18.3	(5.3)	--	76.6	(16.8)	--
Global assessment of quality of death (1-5)	423	r = −0.167		0.001	r = 0.070		0.148
Quality of Care							
Global assessment of quality of care							
Very good	272	17.8	(5.4)	0.001	76.3	(16.5)	0.261
Poor, fair, good	161	19.7	(5.1)	--	74.4	(15.4)	--
Poor hygiene Care							
No	285	17.9	(5.5)	0.007	76.4	(16.4)	0.142
Yes	140	19.8	(5.1)	--	73.8	(15.7)	--
Long-term Care Relationships							
Family trusted particular staff member							
No	50	16.2	(5.8)	0.006	81.6	(14.8)	0.008
Yes	383	18.8	(5.3)	--	74.9	(16.1)	--
Family perception of physician communication (7 items, 0-3)	429	r = −0.041		0.304	r = 0.112		0.028
Number of other helpers							
None	193	18.7	(5.3)	0.587	75.5	(16.3)	0.870

		Emotional Strain			Physical Health		
	N	Mean or Correlation	(SD)	p-value [b]	Mean or Correlation	(SD)	p-value [b]
One	123	18.8	(5.6)	0.345	74.8	(15.9)	0.528
2 or more	116	17.9	(5.4)	ref$^{0.640}$	76.5	(16.1)	ref$^{0.797}$
Amount of Involvement							
Days visited resident	432	r = 0.263		<0.001	r = −0.049		0.288
Perceived involvement in care (0-5)	431	r = −0.325		<0.001	r = 0.048		0.322
Preference for involvement							
Be more involved	107	19.4	(4.9)	0.015	73.8	(14.0)	0.108
No change in involvement	310	18.1	(5.6)	ref$^{0.018}$	76.5	(16.5)	ref$^{0.201}$
Be less involved	16	20.3	(3.5)	0.081	72.6	(20.4)	0.332
Potential Secondary Stressors							
Number of dependents							
None	164	16.9	(4.9)	0.002	75.5	(16.3)	0.987
1	148	19.0	(5.6)	0.288	75.9	(16.3)	0.678
2	50	20.6	(5.4)	0.303	74.9	(15.0)	0.899
3 or more	72	19.6	(5.1)	ref$^{<0.001}$	75.8	(16.4)	ref$^{0.939}$
Any financial burden in past year							
No	257	17.1	(5.2)	<0.001		77.7 (16.0)	0.002
Yes	174	20.6	(4.9)	--	72.8	(15.8)	--
Family conflict (8 items,0-3)	433	r = 0.342		<0.001	r = −0.076		0.087
Social Support							
Informal social support - (0-95)	433	r = −0.133		0.002	r = 0.193		<0.001
Staff social support (0-33)	428	r = −0.018		0.518	r =	0.019	0.680
Spiritual social support (0-15)	425	r = −0.111		0.064	r = 0.069		0.171

[a] Sample size for individual characteristics varies slightly because of missing data.

[b] Based on Linear mixed models, controlling for clustering by inclusion of a random effect for facility; these are unadjusted.P-values shown as superscripts are for the overall F-test for the categorical variable with k-1 degrees of freedom where k is the number of categories.

Table 4

Results of Linear Mixed Model of Caregiver Emotional Strain and Evaluation of Potential Mediating Effects of Informal Social Support and Staff Support (N = 402)[a]

		With Potential Mediating Effects					
	Direct Effects: Without Potential Mediators	Social Support		Staff Support		Informal Social Support and Staff Support	
Characteristic	Estimate	Estimate	Percent Change[b]	Estimate	Percent Change[b]	Estimate	Percent Change[b]
Background: Informal caregiver characteristics							
Age (per year)	−0.116 ***	−0.113 ***		−0.117 ***		−0.113 ***	
Male gender	−1.292 **	−1.291 **		−1.293 ***		−1.290 ***	
Race/ethnicity							
White, non-Hispanic (ref)	+	+		*		+	
White, Hispanic	−3.545 *	−3.458 *		−3.565 *		−3.474 *	
Black	−1.093	−1.137		−1.084		−1.129	
Other	1.386	1.509	0.934		1.061		
Education							
College graduate (ref)	**	_ **		**		**	
Some college/trade school	−0.098	−0.076		−0.135		−0.113	
High school or less	−1.765 **	−1.720 **		−1.919 ***		−1.876 **	
Any dependents	1.475 **	1.675 ***	13.6	1.433 **		1.658 ***	12.4
Potential stressors							
Trusted staff member	1.210 +	1.339 *	10.7	0.845	−30.2	0.969	−19.9
Number days visited in last month	0.063 **	0.062 *		0.060 *		0.059 *	
Caregiver involvement	1.031 ***	1.030 ***		1.069 ***		1.092 ***	
Quality of care < very good	1.402 **	1.288 **	−8.1	2.322 ***	65.6	2.226 ***	58.8
Any financial burden	2.606 ***	2.469 ***	−5.3	2.689 ***		2.542 ***	−2.5
Family conflict	1.013 ***	0.959 ***	−5.3	1.085 ***	7.1	1.027 ***	1.4
Potential mediators							
Informal social support		−0.021 +				−0.023 *	
Staff social support				0.105 **		0.108 **	
Facility variance component (*Standard Error*)	1.37 (0.87) +	1.39 (0.87) +		1.26 (0.83) +		1.31 (0.83) +	
Akaike information criterion[c]	2,279.0	2,282.8		2,273.3		2,276.5	

for specified variable; when shown next to a reference category, the overall p-value is for the given characteristic.

Spiritual support was not significantly associated with emotional strain in the multivariable model (coefficient = −0.054; p=0.178), so mediation was not further evaluated.

[a]Mixed models include random effect for facility and fixed effects shown; N is the number of residents with complete data on all of the variables shown. The following variables did not meet requirement for inclusion in the multivariable model (p>.10): length of stay, married, relationship to

decedent, employed, symptom burden, course of illness, hospice, global assessment of quality of death, poor hygiene, and preference for involvement.

[b] Percentage change in the regression coefficient for the specified variable compared to the model with no potential mediators; shown only for variables that are p<0.10 in the model with no potential mediators and that were associated with the potential mediator (p<0.10). A negative change indicates the regression coefficient is smaller in absolute value (i.e., closer to 0).

*** =p<0.001;

** =p<0.01;

* =p<0.05;

+ =p<0.10

[c] Akaike Information criterion; smaller value indicates better model fit (Littell et al, 2006)

Table 5

Results of Linear Mixed Model of Caregiver Poorer Physical Health and Evaluation of Potential Mediating Effects of Informal Social Support (*N* = 402)[a]

	Direct Effects: Without Potential Mediators	With Potential Mediating Effects (+ Social Support)	
Characteristic	**Estimate**	**Estimate**	**Percent Change[b]**
Background: Informal caregiver characteristics			
Employed full or part time	−3.880 *	−3.568 *	−8.0
Potential stressors			
Trusted staff member	7.039 **	7.799 **	10.8
Physician communication	−1.567 *	−1.192	−23.9
Any financial burden	4.623 **	3.862 *	−16.5
Potential mediators			
Informal social support		−0.123 **	
Facility variance component (*Standard Error*)	8.06 (9.62)	7.59 (8.99)	
Akaike information criterion[c]	3,529.7	3,518.0	

Neither staff support nor spiritual support was significantly associated with physical health in the multivariable model (coefficient for staff support 0.026, p=0.793;coefficient for spiritual support = 0.150, p=0.289), so mediation by these support measures was not further evaluated.

[a]Mixed models include random effect for facility and fixed effects shown; N is the number of residents with complete data on all of the variables shown. The following variables did not meet requirement for inclusion in the multivariable model (p>.10): caregiver's age, relationship to decedent, education, family conflict,and preference for involvement

[b]Percentage change in the regression coefficient for the specified variable compared to the model with no potential mediators; shown only for variables that are p<0.10 in the model with no potential mediators and that were associated with the potential mediator (p<0.10).. A negative change indicates the regression coefficient is smaller in absolute value (i.e., closer to 0).

[c]Akaike Information criterion; smaller value indicates better model fit (Littell et al 2006)

*** p<0.001;

** p<0.01;

* p<0.05; +p<0.10 for specified variable; when shown next to a reference category, the overall p-value is for the given characteristic.